



EMERALD STUDIES
IN THE HUMANITIES,
AGEING AND LATER LIFE

MOVIES,
MUSIC AND
MEMORY

*Tools for Wellbeing
in Later Life*

EDITED BY
*Julia Hallam
and Lisa Shaw*

MOVIES, MUSIC AND MEMORY

Emerald Studies in the Humanities, Ageing and Later Life

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MOVIES, MUSIC AND MEMORY

Tools for Wellbeing
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**Emerald Studies in the
Humanities, Ageing
and Later Life**

EDITED BY

JULIA HALLAM

University of Liverpool, UK

LISA SHAW

University of Liverpool, UK



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For our parents

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ABOUT THE CONTRIBUTORS

Julia Hallam is Professor Emerita in the Department of Communication and Media, School of the Arts, University of Liverpool. She has written widely on issues of gender, representation and aesthetics in film and media and on women as creators and producers of film and television. More recently, she led three AHRC-funded projects on film, memory and urban space, working with amateur and independent filmmakers, the North West Film Archive and the British Film Institute. She has curated exhibitions for the National Museum of Medicine, Washington DC, and the Museum of Liverpool. In an earlier life, she trained as a nurse and health visitor and led the Liverpool arm of the Neighbourhood Health Project (1977–1979), one of the first projects in the UK to employ community health workers to co-ordinate new initiatives on health and social care issues.

Lisa Shaw is Professor of Brazilian Studies in the Department of Modern Languages and Cultures at the University of Liverpool. Her research interests are Brazilian cultural history, with an emphasis on twentieth-century popular music, theatre and film, and in particular from a transnational perspective. She has written books on the social history of Brazilian samba music, the film star Carmen Miranda and popular Brazilian cinema from the 1940s and 1950s. She leads the *Cinema*,

Memory and Wellbeing impact project, which explores the use of music and film as reminiscence tools to improve the emotional wellbeing of the older population, including those living with a dementia diagnosis, and involves outreach initiatives on Merseyside, UK, and in the states of Rio de Janeiro and São Paulo, Brazil.

Dr Jacqueline Waldock is a researcher at the University of Liverpool. She previously studied Music at Lancaster University and went on to complete a doctorate at the University of Liverpool in Musicology and Composition. Her research focusses on sounds of everyday life, listening cultures and soundscape composition as an ethnographic tool. Selected publications include: Waldock, J. (2016). Hearing urban change. In L. Black & M. Bull (Eds.), *Auditory cultural reader* (2nd revised edition). Bloomsbury and Waldock, J. (2016). Crossing the boundaries: Community composition and sensory ethnography. *Senses and Society*, 11(1), 60–67.

Sara Cohen is a Professor at the University of Liverpool where she holds the James and Constance Alsop Chair in Music and is Director of the Institute of Popular Music. She has a DPhil in Social Anthropology from Oxford University and is author of *Rock Culture in Liverpool* (1991) and *Decline, Renewal and the City in Popular Music Culture* (2007), co-author of *Harmonious Relations* (1994) and *Liverpool's Musical Landscapes* (2018) and co-editor of *Sites of Popular Music Heritage* (2014). She has specialized in interdisciplinary research on popular music, with a particular interest in ethnographic approaches and research on place, heritage, memory and ageing.

Helena Culshaw is an independent occupational therapist and former chair and vice-chair of the Royal College of Occupational Therapists. Helena has previously managed services in

the NHS in both hospital and community services including mental health.

Dr Clarissa Giebel is a dementia care researcher, based at the University of Liverpool at the National Institute for Health Research ARC NWC (Applied Research Collaboration North West Coast). Her main research focus is on enabling people with dementia to live independently for longer in the community, thereby addressing potential health inequalities that might affect access to the right care at the right time. She is leading on a number of projects in this field, and works closely with the Netherlands, Australia, Colombia and Chile in addressing health inequalities on a global level. Public involvement is a key component of all her work, and she is actively working with people living with dementia and family carers in all her projects. She conducts independent research funded by the NIHR ARC NWC, and the views expressed in this book are her own, not necessarily those of the National Institute for Health Research or the Department of Health and Social Care.

Ros Jennings is Professor of Ageing, Culture and Media and Co-Director of the Women, Ageing and Media (WAM) Research Centre, University of Gloucestershire.

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PREFACE

HELENA CULSHAW*

My involvement with this project has been as a catalyst between the contributing authors and practitioner occupational therapists in the North West of England and more specifically those working with dementia patients in the Mersey Care NHS Foundation Trust. When I met with Professor Lisa Shaw and Dr Jacqueline Waldoock they told me about the project with older people and the development of the *Cinema, Memory and Wellbeing* toolkit. I could immediately see the potential for their use within Occupational Therapy services for older people and those living with dementia as part of a range of interventions using meaningful activity to trigger memories and promote wellbeing.

This is a well-researched project involving activities suitable for use within any health interventions by therapists who are always keen to investigate the use of occupation-focussed activities that are evidence-based and that will assist their users in being able to participate as they choose. I was particularly struck by the two creative workshops that the contributors held on Merseyside, where they enabled the

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participants, along with their therapists and carers, to use a variety of crafting techniques to make decorative objects related to the film prior to their viewing it. This created great opportunities for engaging individuals, prompting childhood memories and promoting interaction between the participants. The potential I had seen at the first meeting had come to fruition.

The joy of this book and toolkit is that it can be used to very good effect by staff and carers in nursing and care homes and day centres for older people, as it provides good guidance and tips as well as demonstrating how to use equipment and resources that are easily available every day. Occupational therapists have long used creative activities as meaningful occupation within their interventions with service users, including older people. The outcome of this project is complementary to occupational therapy, and I would recommend its usefulness within specific interventions in health and care settings by occupational therapists seeking to extend the range of opportunities for service users.

Reminiscence work with older people and people living with dementia is constantly moving forwards. As the age profile changes, so does the era of the movies and the music that can be profitably used in reminiscence work. This project shows that these principles and the toolkit could be applied to re-connect people with memories from the eras of Carmen Miranda or Madonna, of Gershwin or Gary Barlow.

INTRODUCTION: MAPPING THE TERRAIN – FILM AND MUSIC IN THIRD-AGE CARE

Julia Hallam, Lisa Shaw and Jacqueline Waldock

AGEING AND DEMENTIA: THE UK AND GLOBAL CONTEXTS

The ageing population and the increase in those living with a dementia diagnosis present a major societal challenge and threat to the systems and institutions that maintain the wellbeing and welfare of older members of modernized societies. The number of people in England and Wales aged over 65 years will increase by roughly 19.4% by 2025. Notably, the number of people in the UK aged over 85 years is likely to double in the next 25 years. These projections are supported by recent high-profile reports, including one in *Lancet Public Health*, urging the government ‘to give urgent consideration to options for more cost-effective health and social care provision in all its forms’, and emphasizing that ‘informal and home care require stronger policy support’ (Castillo et al., 2017, p. 312). As we get older in life, the loss of partners and friends to share our memories with, combined with the increasing chance of health and mobility

issues, can cause loneliness, anxiety and distress. Coupled with this is the fact that people are generally living longer, families are more mobile and adult children sometimes live far away from their ageing parents. In the UK, increased life expectancy is already giving rise to a crisis in care that can leave older people unsupported in their homes, and unable to afford community-based or residential care. Attempts to help alleviate loneliness and its associated emotional difficulties by providing activities that bring people together, be it in community day-care facilities or the communal areas of retirement and nursing homes, have mushroomed in recent years. Despite funding challenges, charities, social enterprise initiatives and public organizations are finding ways to enable care workers, carers and volunteers to become involved in providing a wide range of activities for older people, many of them based on various forms of reminiscence and memory work. Participation in these activities, often drawing on artefacts and images from the past, has been shown to demonstrably enhance the wellbeing of those taking part, both the carers and the cared for.

Caring for a growing population of older people, and particularly those living with dementia-related cognitive impairment, is a major global health and development challenge; as well as impacting on the lives of those with a dementia diagnosis, it is now widely recognized that care-givers and family members need both emotional and practical support. This threat to welfare is particularly acute in developing countries and emerging economies like Brazil, whose senior population is predicted to exceed 32 million by 2025 (US Census Bureau), where the vast majority of people aged 60 years and over (73%) and of those aged 80 years and over (80%) are currently dependent on the poorly funded, increasingly precarious, state health-care system (SUS), and where there are over a million people living with

a dementia diagnosis (although it is widely recognized that under-diagnosis of dementia is high in low- and middle-income countries). It is estimated that there is only one geriatrician per 22,000 older people in Brazil, and that large geographical areas have virtually non-existent geriatric coverage (Garcez-Lemme & Deckers Lemme, 2014, p. 3). Only 1% of the growing ageing population of this country, the largest nation in South America, with a population of over 200 million people, live in long-term care homes, and frequently people with dementia live with their families, with some support from civil or religious organizations, and home visits from the *Programa Saúde da Família* (PSF – Family Health Programme). As Garcez-Lemme and Deckers-Lemme write: ‘The problem of the elderly in Brazil requires solutions applicable to a rapidly growing population, with [...] very limited financial resources and scant family support. Solutions must be simple, easily applicable, with a good cost-benefit relationship’ (2014, p. 3).

Care for people living with dementia and for the family members who care for them differs greatly from one national context to another. As Clarissa Giebel, one of the contributors to this book, has noted: ‘Some European countries have only recently implemented national dementia strategies, and structures and content of services vary greatly, which may suggest that countries need to address issues of independence and well-being in dementia in the light of these’ (Giebel et al., 2014). The Right Time Place Care study has explored dementia care provision at the transition point from home residence to living in a care home, examining and comparing the factors that affect care home admission and costs for people living with dementia across the UK, Germany, the Netherlands, Spain, Estonia, Sweden, France and Finland (Verbeek et al., 2012). One of the many symptoms which requires support in dementia care

are difficulties with basic activities such as getting dressed, as well as more complex activities, such as dealing with personal medication and finance management, or even making a hot drink. People with dementia in its earliest stages may lose the ability to initiate and perform these more complex activities, along with other manifestations of cognitive deterioration, but are still able to carry out the more basic tasks, such as washing themselves and dressing, until the disease is more advanced. Clarissa Giebel led a study that looked at these symptoms across the eight countries listed above, concluding, for example, that the ability to bathe and dress oneself deteriorates earlier than the ability to feed oneself (Giebel et al., 2014). She and her research team found that not being able to engage in certain daily activities can affect the quality of life of the person living with dementia, but that these effects vary from country to country, with quality of life only being linked to everyday task performance in the early stages of dementia in some countries, such as Estonia. Quality of life and quality of care in general were found to be highest in the UK and Sweden, and lowest in Estonia and Spain (Beerens et al., 2014). This clearly highlights that within Europe, possibly due to cultural factors as well as system variations in care provision, people with dementia receive different levels of care. These variations can also lead to differences in predictors of care home access across Europe. Whilst caregiver burden and difficulties in engaging with activities of daily living are the main predictors of care home admission relating to dementia across Europe, there are strong country variations. In Germany, for example, depressive symptoms predicted care home admission, whereas this was not the case for France or the Netherlands (Verbeek et al., 2015).

There is clearly a great deal to be done in terms of sharing learning and best practice between different

countries, even within developed Europe, and an even more urgent need to disseminate expertise and practical applications of research findings to middle- and low-income countries. It is our hope that, having already translated our best-practice toolkit into Portuguese, we can in the future make it available in a range of other languages, tailored to the specificities of other national contexts, including parts of the developing world.

SOCIAL PRESCRIBING, THE ARTS AND CO- PRODUCTION

One contribution to addressing the crisis in social care in the UK is the development of so-called social prescribing, defined by the CentreForum Mental Health Commission in 2014 as ‘a mechanism for linking patients with non-medical sources of support within the community’ (CentreForum, online). According to the Kings Fund, social prescribing is designed to enable general practitioners (GPs), nurses and other primary care professionals, such as occupational therapists (OTs), to refer people to a range of local, non-clinical services. These can be activities such as arts and crafts, dance or gardening, wellbeing sessions (meditation, mindfulness, yoga and tai chi, for example) and other services such as diet advice and befriending (The Kings Fund, 2017, online). Social prescribing focusses on prevention of illness and the promotion of wellness rather than treatment, and reflects a paradigm shift that has taken place in our understanding of health and health care in the UK and beyond, one that, as Lisa discovered, has also gathered momentum in Brazil. Flagship arts-based social prescribing projects that have brought universities into close partnership with cultural institutions in the UK include the Arts and Humanities

Research Council (AHRC)-funded Museums on Prescription programme, involving University College London and Canterbury Christ Church University (from which the ‘wellbeing umbrellas’ measures we tried out in one of our projects in Brazil, discussed in Chapter 3, were adapted). There was initially a certain reluctance among GPs to embrace the concept of social prescribing, a reluctance that appears to be less obvious among nursing staff and link workers; as Lisa and Jacky heard at a regional conference of OTs in 2019, there is still work to be done in reassuring health professionals of the benefits of social prescribing and, perhaps more importantly, how it can be embraced to improve their own working lives.

Social prescribing aims to provide a holistic approach to health care by helping people to take more control of their personal health needs. It recognizes that many of the aspects involved in maintaining a healthy lifestyle are determined by a range of economic, social and environmental factors that are beyond the control of any single individual. It is designed to help people with a wide range of social, emotional and/or practical needs, including those with mild or long-term mental health issues and those who are socially isolated. In 2014 the creation of an All-Party Parliamentary Group on Arts, Health and Wellbeing further evidenced the emphasis at national level of the promotion of wellness via arts-based interventions and has strengthened arguments for their adequate funding (culturehealthandwellbeing.org.uk). Furthermore, in 2018 the UK Government’s Health and Wellbeing Fund awarded £4.5 million to 23 social prescribing projects, which led to funding for social prescribing link workers based within NHS trusts to be allocated for the first time in 2019.

Many social prescribing activities are run locally by voluntary groups and charitable organizations that have a

particular focus on improving mental health and wellbeing. The standard model is for interventions to be run over a 10-week period and evaluated by end-of-project interviews with participants and facilitators. This 10-week referral model has its limitations, and generally speaking the longer-term benefits of such interventions require further research. A notable exception of a long-term project with a strong research dimension is the work carried out by The Reader, a global organization based in Liverpool, which has produced impressive results when using shared reading activities with people living with dementia, amongst many other groups. As the organization's website states in relation to the conclusions of a six-month study funded by the Headley Trust:

the literature-based intervention provided by Shared Reading produces a significant reduction in dementia symptoms and benefits the quality of life of both the residents and staff carers. The quantitative and qualitative research also found that short- and long-term memory was positively influenced, listening skills were improved and the provision of activity by an external organisation enhanced patient care
(Gallagher, 2017)

There is a growing body of evidence of the benefits of all forms of arts-based or cultural activity for older adults and those living with dementia, stemming from research conducted across a wide range of disciplines associated with the wellbeing and care of these groups in society, such as psychology, gerontology, psychiatry and the associated professions of nursing and occupational therapy. Research from various perspectives has shown that all of these activities create positive effects in terms of improved mood and cognitive ability (see, for example, Young, Camic, & Tischler, 2016).

These positive effects can be further enhanced by involving participants in the planning and elaboration of the activities in question, what the academic literature refers to as co-design, co-curation or co-production. As we recommend in the toolkit that we designed based on the various pilot projects discussed in this book (downloadable from Emerald's website) – which was created by using a user-centred approach – the involvement of stakeholders in the preparation and design of well-being interventions using music and/or film adds a further therapeutic benefit. For those living with dementia, involvement in creative activities has proved to be particularly powerful. Furthermore, arts-based interventions, where the emphasis is taken away from formal education and fact-based learning, has been shown to be a very effective way of assisting the dementia care workforce (Windle et al., 2019). Arts-based activities, like the creative workshops organized at the Plaza Community Cinema on Merseyside as part of the 'Cinema, Memory and Wellbeing Festival' discussed in Chapter 3, optimize and celebrate the abilities that people with dementia still have, providing more of a 'level playing field' that allows them to engage, express themselves and connect with other people.

The projects that we have piloted in the UK and Brazil are a contribution to a growing international body of knowledge that demonstrates that various forms of arts-based or culturally focussed activities make a positive difference to the emotional wellbeing of senior members of society, particularly those living alone or in institutions, and those living with a dementia diagnosis. A dementia study published in the health journal *PLOS Medicine* concluded: 'relatively simple things, if implemented robustly, can actually make a real difference to people's quality of life', particularly if this involves interaction and learning about people's interests and abilities, and can 'help reduce costs, both in care homes and the wider social